

## Appendix 8

### Availability of Services To Assist Families

According to the U.S. Census Bureau (2000), 47% of first marriages fail and 57% of all marriages end in divorce. Families with a child with autism or other disabilities report more stress on the marriage than usual. (Seligman and Darling, Ordinary Families, Special Children, 1997.) Parents have to deal with the normal stresses in marriage as well as trying to get a diagnosis and treatment, along with incurring financial burdens to provide the necessary help. One or both parents become so involved in the time consuming task of minute-by-minute required care that a child with autism needs that communication and time to work on the marriage relationship can become non-existent. Parents who have what appears to be a typical child at birth, but who later find the child is autistic, go through a grieving process similar to as if they had lost a child. They grieve for the loss of the typical child they thought they had and for the lifestyle they expected for their family. Siblings can become resentful of the time and attention given to the child with autism and the family tends to isolate themselves from friends, relatives and their community because their child's behaviors are so unpredictable.

Family Support America defines family support as “as set of beliefs and approaches to strengthening and empowering families and communities so that they can foster the optimal development of children, youth and adult family members.” Many families cite parent to parent, sibling support, and similar organizations as critical to their sense of well being and connectedness. Family resilience is strengthened through family supports and social connection with other families who experience ASD. Information is a critical need. Many resources are available, but families have trouble identifying where to start when they first receive the diagnosis.

All families experience a series of triumphs and challenges in raising their children, but families raising children and youth with special health care needs have an additional set of challenges. (See Bronheim, Goode, and Jones, National Center for Cultural Competence, Policy Brief on Cultural and Linguistic Competence in Family Supports, Spring 2006). Those challenges often intensify when the special health care need is ASD. Parents of children with ASD cite challenges which include:

- Managing complex and atypical behavioral and emotional problems around the clock;
- Being isolated from community and friends;
- Reduction in work hours due to needs of child and lack of childcare;
- Inability to access health insurance to cover needed therapies;
- Providing care and support beyond the traditional childhood years (including elderly family members caring for adults).

Parents and professionals who presented to the task force, as well as task force members themselves, identified the need for increased focus on providing culturally and linguistically effective family supports for individuals with ASD. This was an across-the-board statement. For some parents, it is difficult to do even routine activities because they cannot take their child into public settings. Needs vary across the spectrum, from highly visible to nearly invisible, but all are challenging. One panelist cited how difficult it is, as an adult with Aspergers, to maintain employment and to balance the need for connection with the need for being separate. Other panelists described how in their culture it is seen as a weakness to ask for help. Another explained that the stigma of disability is still a barrier for some families, who don't want to draw attention to their child. More family supports are necessary. Please see the minutes from the parent and individuals with ASD panel in the appendix.